

July 18, 2001

The Honorable Greg Ganske  
United States House of Representatives  
1108 Longworth House Office Building  
Washington, D.C. 20515

The Honorable John Dingell  
United States House of Representatives  
2328 Rayburn House Office Building  
Washington, D.C. 20515

VIA FAX

Dear Representatives Ganske and Dingell:

On behalf of the 30,000 people living with cystic fibrosis (CF), the Cystic Fibrosis Foundation would like to express its appreciation for the important protections for people with CF that are included in H.R. 526, the Bipartisan Patient Protection Act of 2001. These protections will ensure that people with CF have access to specialty care and medications in order to enjoy longer, healthier lives.

Cystic fibrosis is a genetic disease, which affects the respiratory, digestive, and reproductive systems. The life expectancy has increased over the past few decades from less than ten years to approximately 30 years. Although there has been progress in treatment of CF, the life expectancy is still unacceptably limited. The CF Foundation is committed to curing this disease, a commitment it will support with an investment of more than \$59 million in CF research this year alone.

Without access to specialized centers of care, individuals with CF will not be able to reap the benefits of medical research. The CF Foundation has established and accredited a network of more than 115 care centers at many top academic medical centers around the country. The physicians at these centers are expert in caring for people with CF, particularly in the more advanced stages of illness when patients may have to consider the need for lung transplants. A key reason that life expectancy for these patients has increased and quality of life has improved is access to health professionals with specific knowledge of CF. We are pleased that you have included in H.R. 526 provisions on timely access to specialty care to ensure that patients with CF will continue to have access to life-saving medical care. Individuals with CF must be able to secure specialty care even if providers are outside the plan and should enjoy a standing referral for specialty care that does not have to be renewed more frequently than on an annual basis.

**National Office**

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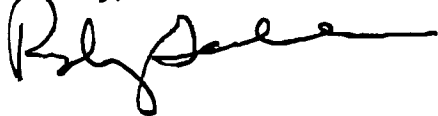
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Quality CF care also requires access to life-saving treatments. Individuals with CF should not have their treatment options limited by restrictive formularies. We applaud your efforts to ensure that individuals will not face unreasonable barriers to prescription medications. In addition, provisions in H.R. 526 that ensure access to and coverage for clinical trials, including those regulated by the Food and Drug Administration (FDA), are vital to improved health care and quality of life for our patients. Clinical trials answer critical questions about optimal care for those with CF and yield data for the approval of new products by the FDA, and third-party reimbursement for routine patient care costs must be guaranteed so that accrual will not be inhibited and the speed of research will not be adversely affected.

We appreciate your leadership in introducing H.R. 526. We look forward to working with you and your colleagues to ensure the passage of a strong patient protection bill. Please contact Suzanne Pattee, Vice President for Public Policy and Patient Affairs, at 301-907-2548, if you have questions.

Sincerely,

A handwritten signature in black ink, appearing to read "R. Beall", with a long horizontal flourish extending to the right.

Robert J. Beall, Ph.D.  
President and CEO